

As Amended by House Committee

Session of 2007

HOUSE BILL No. 2224

By Social Services Budget Committee

1-25

10 AN ACT concerning the department of health and environment; relating
11 to education and screening for congenital hypothyroidism, galactose-
12 mia, phenylketonuria and other genetic diseases and disorders; assis-
13 tance for certain expenses; amending K.S.A. 2006 Supp. 65-180 and
14 repealing the existing section.
15

16 *Be it enacted by the Legislature of the State of Kansas:*

17 Section 1. K.S.A. 2006 Supp. 65-180 is hereby amended to read as
18 follows: 65-180. The secretary of health and environment shall:

19 (a) Institute and carry on an intensive educational program among
20 physicians, hospitals, public health nurses and the public concerning con-
21 genital hypothyroidism, galactosemia, phenylketonuria and other genetic
22 diseases detectable with the same specimen. This educational program
23 shall include information about the nature of such conditions and exam-
24 inations for the detection thereof in early infancy in order that measures
25 may be taken to prevent the mental retardation or morbidity resulting
26 from such conditions.

27 (b) Provide recognized screening tests for phenylketonuria, galacto-
28 semia, hypothyroidism and such other diseases as may be appropriately
29 detected with the same specimen. The initial laboratory screening tests
30 for these diseases shall be performed by the department of health and
31 environment *or its designee* for all infants born in the state. Such services
32 shall be performed ~~without charge for a fee of not more than \$30 per~~
33 ~~newborn~~ **without charge.**

34 (c) Provide a follow-up program by providing test results and other
35 information to identified physicians; locate infants with abnormal new-
36 born screening test results; with parental consent, monitor infants to as-
37 sure appropriate testing to either confirm or not confirm the disease sug-
38 gested by the screening test results; with parental consent, monitor
39 therapy and treatment for infants with confirmed diagnosis of congenital
40 hypothyroidism, galactosemia, phenylketonuria or other genetic diseases
41 being screened under this statute; and establish ongoing education and
42 support activities for individuals with confirmed diagnosis of congenital
43 hypothyroidism, galactosemia, phenylketonuria and other genetic dis-

1 eases being screened under this statute and for the families of such
2 individuals.

3 (d) Maintain a registry of cases including information of importance
4 for the purpose of follow-up services to prevent mental retardation or
5 morbidity.

6 (e) Provide, within the limits of appropriations available therefor, the
7 necessary treatment product for diagnosed cases for as long as medically
8 indicated, when the product is not available through other state agencies.
9 In addition to diagnosed cases under this section, diagnosed cases of ma-
10 ple syrup urine disease shall be included as a diagnosed case under this
11 subsection. Where the applicable income of the person or persons who
12 have legal responsibility for the diagnosed individual meets medicaid el-
13 igibility, such individuals' needs shall be covered under the medicaid state
14 plan. Where the applicable income of the person or persons who have
15 legal responsibility for the diagnosed individual is not medicaid eligible,
16 but is below 300% of the federal poverty level established under the most
17 recent poverty guidelines issued by the United States department of
18 health and human services, the department of health and environment
19 shall provide reimbursement of between 50% to 100% of the product
20 cost in accordance with rules and regulations adopted by the secretary of
21 health and environment. Where the applicable income of the person or
22 persons who have legal responsibility for the diagnosed individual exceeds
23 300% of the federal poverty level established under the most recent pov-
24 erty guidelines issued by the United States department of health and
25 human services, the department of health and environment shall provide
26 reimbursement of an amount not to exceed 50% of the product cost in
27 accordance with rules and regulations adopted by the secretary of health
28 and environment.

29 (f) Provide state assistance to an applicant pursuant to subsection (e)
30 only after it has been shown that the applicant has exhausted all benefits
31 from private third-party payers, medicare, medicaid and other govern-
32 ment assistance programs and after consideration of the applicant's in-
33 come and assets. The secretary of health and environment shall adopt
34 rules and regulations establishing standards for determining eligibility for
35 state assistance under this section.

36 (g) (1) Except for treatment products provided under subsection (e),
37 if the medically necessary food treatment product for diagnosed cases
38 must be purchased, the purchaser shall be reimbursed by the department
39 of health and environment for costs incurred up to \$1,500 per year per
40 diagnosed child age 18 or younger at 100% of the product cost upon
41 submission of a receipt of purchase identifying the company from which
42 the product was purchased. For a purchaser to be eligible for reimburse-
43 ment under this subsection (g)(1), the applicable income of the person

1 or persons who have legal responsibility for the diagnosed child shall not
2 exceed 300% of the poverty level established under the most recent pov-
3 erty guidelines issued by the federal department of health and human
4 services.

5 (2) As an option to reimbursement authorized under subsection
6 (g)(1), the department of health and environment may purchase food
7 treatment products for distribution to diagnosed children in an amount
8 not to exceed \$1,500 per year per diagnosed child age 18 or younger. For
9 a diagnosed child to be eligible for the distribution of food treatment
10 products under this subsection (g)(2), the applicable income of the person
11 or persons who have legal responsibility for the diagnosed child shall not
12 exceed 300% of the poverty level established under the most recent pov-
13 erty guidelines issued by the federal department of health and human
14 services.

15 (3) In addition to diagnosed cases under this section, diagnosed cases
16 of maple syrup urine disease shall be included as a diagnosed case under
17 this subsection (g).

18 (h) The department of health and environment shall continue to re-
19 ceive orders for both necessary treatment products and necessary food
20 treatment products, purchase such products, and shall deliver the prod-
21 ucts to an address prescribed by the diagnosed individual. The depart-
22 ment of health and environment shall bill the person or persons who have
23 legal responsibility for the diagnosed patient for a pro-rata share of the
24 total costs, in accordance with the rules and regulations adopted pursuant
25 to this section. ~~The department of health and environment and the Kansas~~
26 ~~health policy authority shall combine the purchasing resources for the~~
27 ~~purpose of this subsection and shall enter into a joint contract for the~~
28 ~~purchase of all products for both medicaid and nonmedicaid eligible cli-~~
29 ~~ents.~~

30 (i) *Not later than July 1, 2008, the secretary of health and environ-*
31 *ment shall adopt rules and regulations as needed to require, to the extent*
32 *of available funding, newborn screening tests to screen for disorders listed*
33 *in the core uniform panel of newborn screening conditions recommended*
34 *in the 2005 report by the American college of medical genetics entitled*
35 *“Newborn Screening: Toward a Uniform Screening Panel and System” or*
36 *another report determined by the department of health and environment*
37 *to provide more appropriate newborn screening guidelines to protect the*
38 *health and welfare of newborns.*

39 (j) *In performing the duties under subsection (i), the secretary of*
40 *health and environment shall appoint an advisory council to advise the*
41 *department of health and environment on implementation of subsection*
42 *(i).*

43 (k) *The department of health and environment shall periodically re-*

1 *view the newborn screening program to determine the efficacy and cost*
2 *effectiveness of the program and determine whether adjustments to the*
3 *program are necessary to protect the health and welfare of newborns and*
4 *to maximize the number of newborn screenings that may be conducted*
5 *with the funding available for the screening program.*

6 Sec. 2. K.S.A. 2006 Supp. 65-180 is hereby repealed.

7 Sec. 3. This act shall take effect and be in force from and after its
8 publication in the Kansas register.